



# The Dandy-Walker Alliance Newsletter

Issue 7 | February 18, 2023 | [dandy-walker.org](http://dandy-walker.org)

## Live Q&A with Dr. Kimberly Aldinger of Seattle Children's

On March 11, the Dandy-Walker Alliance is hosting a webinar with Dr. Kimberly Aldinger, PhD, of Seattle Children's Research Institute.

Dr. Aldinger is one of the top Dandy-Walker researchers in the world, and is using exome and whole genome sequencing to uncover the genetic causes of Dandy-Walker. You can learn more about her work on Dandy-Walker and other neuro-developmental disorders [here](#).

This live Q&A webinar is a perfect opportunity to ask Dr. Aldinger questions about her research, Dandy-Walker genetics, common associated conditions and diagnoses, cerebellar anatomy, and much more.

The live webinar will take place on Saturday, March 11, 2023 at 6 p.m. EST. [Registration is open now for this free event.](#)

For those unable to attend, you may submit questions ahead of time at the registration link, and a recording will be available on our YouTube channel the week after the event.

Please direct any questions about the webinar and registration to [chris.rogers@dandy-walker.org](mailto:chris.rogers@dandy-walker.org).

## Understanding Dandy-Walker Genetics

A LIVE Q&A WITH  
**Dr. Kimberly Aldinger, PhD**  
SEATTLE CHILDREN'S RESEARCH INSTITUTE

Saturday, March 11 | 6 p.m. EST  
Register now at [dandy-walker.org/webinar](http://dandy-walker.org/webinar).



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**Welcome to the Dandy-Walker Alliance Newsletter!**  
**Each month we'll recap the big Dandy-Walker stories, highlight community members who are making a difference, and give updates on research, events, and more!**

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### Join our Contact List!

The Dandy-Walker Alliance Email and Contact List will keep you up to date on all organizational news and updates.

Plus, registering for the contact list allows us to connect you with other Dandy-Walker families so that you can create your own support network right in your home town or state! Register at [www.dandy-walker.org/email](http://www.dandy-walker.org/email) or scan the code below!







# A Dozen Donuts for Dandy-Walker

Want to satisfy your sweet tooth and support the Dandy-Walker Alliance at the same time? Order a dozen Krispy Kreme donuts and half of the proceeds will go to the Dandy-Walker Alliance for research, awareness, and family support.

You'll be sure to be a hit with your family, friends, coworkers, and whoever else is the beneficiary of your dozen donuts.

It's simple. All you have to do is place an order through the link to the right. You'll be emailed a code which you can take to the register at your local Krispy Kreme store to redeem a set of fresh glazed donuts!

This promotion runs through the end of February so make sure to place your donut orders soon!



Scan to order or visit  
[dandy-walker.org/donuts](https://dandy-walker.org/donuts)



## Host Your Own Dandy-Walker Fundraiser!

*Want to support families around the world, spread awareness, and fund research into the genetic causes of Dandy-Walker?*

**Sign up to host a Dandy-Walker fundraiser today!**

We'll help you figure out the best event for your style and resources – a walk/run, a bake sale, a restaurant fundraiser, a Facebook fundraiser, or whatever else floats your boat. Then, ***we'll build you a personalized fundraising page*** that you can send out to all of your friends and family!



Email [chris.rogers@dandy-walker.org](mailto:chris.rogers@dandy-walker.org) or call 301-775-5853 to brainstorm the possibilities and get started!

## Thank You, Corporate Partners!



Medtronic

# Paula Muller Prepares for New York Half

For the second year in a row, Paula Muller is running the New York City Half Marathon as a fundraiser for the Dandy-Walker Alliance.

Paula's 16-year-old son, Andrew, was diagnosed with Dandy-Walker shortly after birth. After years of doctor's appointments, therapies, and specialized programs, he is now thriving – the recent winner of his high school's Student of the Month award.

An avid runner with more than two dozen big races under her belt, Paula

decided last year to run the New York Half for the Dandy-Walker Alliance, ultimately raising more than \$15,000 for awareness and research.

She says turning the event into a fundraiser gave her a greater sense of purpose when she ran last year, prompting her to do it all again this year. This year's race is on March 19.

[Learn more about her and Andrew's story here](#), and [make a donation to the Dandy-Walker Alliance to support her efforts!](#)



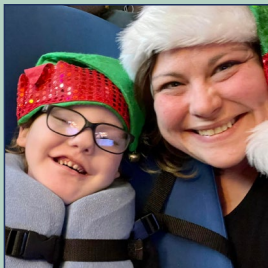
**Paula Muller and her son Andrew, both at left, with her husband, stepdaughter, and other son. Photo courtesy of Paula Muller.**

## Share Your Story with the Dandy-Walker Community!

We have restarted the [Dandy-Walker Alliance YouTube channel](#) and are dedicated to sharing your stories on there. Executive Director Chris Rogers is working on a series of video interviews with Dandy-Walker families across the country and beyond, highlighting both the struggles and successes that come with Dandy-Walker.

Our video interview with Paula Muller, featured above and [linked here](#), was our first in this series. We are looking for other families who are willing to share their stories and serve as an inspiration to our community. This is a great opportunity to support, connect with, and give back to other families facing similar struggles and journeys.

If you're interested in participating or learning more, please email [chris.rogers@dandy-walker.org](mailto:chris.rogers@dandy-walker.org) to set up a preliminary call.



## We Want Your Feedback

Share your ideas and let us know how we can support **your** family this year at [dandy-walker.org/2023survey](https://dandy-walker.org/2023survey).







# Your imaging can help train the Bionauts!

Over the past few months, the Dandy-Walker Alliance has collaborated with Bionaut Labs as they investigate a novel treatment for obstructive hydrocephalus associated with Dandy-Walker Syndrome.

In this new treatment, a micro-scale robot known as a Bionaut would be delivered into the CSF space at the base of the skull and guided by an external computerized magnetic propulsion system to pierce the Dandy-Walker cyst, relieving obstruction and normalizing flow of cerebrospinal fluid.

While the Bionaut technology is still in its early stages, the goal is to introduce it as a new, less-invasive standard of care for hydrocephalus treatment.

In order to develop the Bionaut system to the point where clinical trials can be conducted, Bionaut Labs needs images of classical cranial cysts in Dandy-Walker patients who have developed hydrocephalus. These images will help the Bionaut engineering team better understand the cyst anatomy and in turn properly train the devices and optimize their performance.

All images are shared and used confidentially. Those who participate will be helping develop a treatment that could help people around the world facing complications of Dandy-Walker and hydrocephalus, along with numerous other types of conditions and diseases.

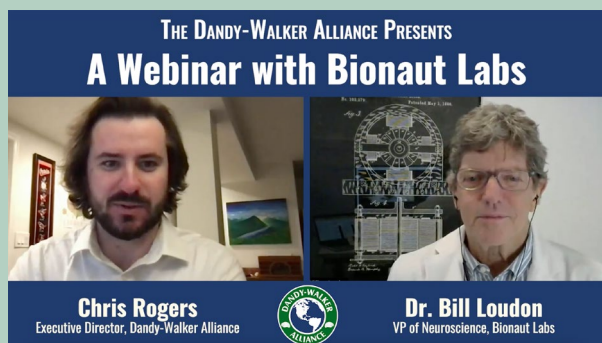
## Get Involved Today!

Confidentially share your head imaging (MRI or CT) with Bionaut Labs to help them train the Bionauts and advance a potential new standard of care for hydrocephalus.

Express your interest at the [link here](#) or use the QR code on the right.



## Learn More About the Bionauts



Hear from Dr. Bill Loudon, VP of Neuroscience at Bionaut Labs, about the device's development and how it can make an impact in our community.



BIONAUT  
LABS



**Collaboration Between  
the Dandy-Walker Alliance  
and Bionaut Labs**

Learn about the Bionaut devices and our collaboration with Bionaut Labs.



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